

COMMUNICATING TOGETHER

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A QUARTERLY MAGAZINE ABOUT AUGMENTATIVE AND ALTERNATIVE COMMUNICATION

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NOLA MILLIN



From Shirley McNaughton
and Peter Lindsay

It's happening! We have often expressed our desire to share the content of **Communicating Together** more and more with consumers. When Nola Millin offered to write the editorial for this issue, we enthusiastically responded, "Yes! Wonderful! Thanks!" The editorial is a natural extension of the process of selecting and organizing articles and we are delighted to share the responsibility with Nola. The feedback we have received regarding the March issue edited by Nola has been most gratifying. Look out Nola! We could get used to this!

From Nola Millin

It is a thrill for me to have been asked by Peter and Shirley to write this editorial. First of all, I have to thank both Peter and Colleen (McGaffey) for their help and support. I was privileged to have both Peter & Colleen spend a couple of days with me in Windsor. Without them, this editorial wouldn't have been written.

Those of you who have been faithful readers probably know that for at least the last four years, our June issues usually look a bit different. That's due to the fact that we have our annual editors' meeting in March. At that meeting we discuss new ideas to improve **Communicating Together**. This year, we are giving priority to making our issues more "reader friendly". (I think I just created a new term.) Sometimes we cram too much into one issue resulting in a lot of black. I know from reading other journals, that I appreciate articles that are informative but are enjoyable to read. I tend to look for articles that have a little more white around them. We promise for a less dense format. As you will see from this issue, however, it is not easy for us. We all have so much to say. Above all, we promise to deliver what we feel is quality material.

We are making a few changes in our various sections. We are pleased to welcome the input of Suzanne Clancy. Suzanne is a former teacher and a good friend of Paul Marshall. You will see her contributions in various sections of **Communicating Together** throughout this next year. Another change has come about due to the resignation of Kari Harrington. We decided that, without Kari, the *Living* section should take a sabbatical. Instead of the *Living* section, we now have *Yucks & Wows* — coordinated by yours truly. I'm definitely biased but I think *Yucks & Wows* will provide readers with a few good chuckles and a few "Oh, No's!" What do you think of the "Yucks" for this issue? I'm sharing a favourite cartoon and Jean Blancher describes how trying to communicate by

telephone can sometimes turn into a fiasco. Thanks Jean, for sharing your "Yuck"!

We hope you like the changes. Let us know what you think. We love hearing from our readers.

Now, let's talk about this issue. The theme that we chose for June is Consumer / Professional Relationships or Consumer / Parent / Professional Relationships. I feel it's necessary to point out that at different times of our life everyone engages in consumer / professional relationships. "Professional" persons become consumers (or patients / clients) when they step out of their own professional environment into that of another professional. For example, the AAC clinician becomes a consumer in a doctor's office and so on.

Though, consumer / professional relationships are common to everyone, for someone who has a disability they are a very frequent occurrence. I know in my own life I deal with many professional people. First of all, I have come to the conclusion that there are three types of professional. One group of professionals has individuals who have the needed qualifications in a specific field, e.g. speech language pathologist, doctor, or teacher. The second group contains those who might not have a degree but they have a certain "expertise" in their chosen profession. In my mind they are sometime more professional than the "professionals". Examples in my life would be certain attendants, a couple of drivers who work on the accessible cab, etc. The third group has what I call the "professional professionals". (What a mouthful, I know.)

I dread having to deal with the first group because they tend to be cold and impersonal; they get the job done

and that's it. Individuals in the second and third groups are rare but they are great to work with. These are the professionals who go that "extra step". They let their humanity show since they're truly concerned with the client's (consumer's) needs. Unfortunately, more and more professionals are being limited as to what they can do for clients so they are joining their colleagues in group number one!

The feature article is about a girl named Sheila. Sheila is like me, an AAC user. Rob Haaf wrote the article with just a little input from Geb Verburg and me. As we thought about Sheila's situation with the professionals in her life, I became aware of how blessed I am with most of the professionals who work with me. Like Sheila, I deal with a lot of professionals — AAC clinicians, speech pathologists, doctors, social workers, O.T.'s, P.T.'s, vocational rehab workers, and so on. I have to say that most of the professionals I work with are the ones who fall into group number two or three. They are the ones who focus on me and listen to my input and let me make the final decision. The story of Sheila describes the type of consumer / professional relationship that is a challenge to establish. Yet, I know good consumer / professional relationships do occur. Once you read the article, you'll see why Sheila and I are so much alike. I don't know about *her*, but I know I'm fortunate because a lot of my relationships with professionals have resulted in great friendships.

Speaking of professionals and friendships, Rob Haaf is one of those "professionals" I enjoy having as a friend. He believes in consumers having input and making decisions about AAC devices. Many of his articles reflect this. For this issue, Rob welcomes Jeff Higginbotham back to *Consuming Technology*. Jeff writes about a new way of looking at semantic

compaction and word prediction. I'm sure many AAC users will find this interesting.

The other regular sections in this issue deal with the consumer / professional relationship. *Teaching and Learning* has two separate articles. Colleen and I both felt that the two articles demonstrate good examples of relationships that occur, or that can occur, between the two parties. In the article entitled "Show and Tell" we read about the importance of a teacher letting her students have some control in discussions and in what she teaches them; in turn the teacher becomes the student. I feel this is a quality of a good teacher. The second article, "ABC's for using Augmentative Communication", is a good reminder for everyone that AAC users have things to share and they need to be listened to — a good trait in any relationship. I respect professionals who value my input and want to hear what I have to say.

You will find *Perspectives* and *Paul's Place* similar to each other in many ways. Both sections deal with our theme. Peter Lindsay coordinated the *Perspective* for this issue. He gave consumers and parents of consumers questionnaires to fill out. Some of the questions and answers appear in this issue. Special thanks goes to Sherri Parkins and her students/friends, as well as all the other participants, for their input. There are answers that I'm sure will touch the hearts of everyone and hopefully cause some professionals to examine their approach to consumers and parents. In *Paul's Place*, Paul Marshall and Suzanne Clancy get into a discussion about the consumer / professional relationship. Paul believes that both parties should have equal voices and the consumer's best interest should be given the high priority. Both *Perspectives* and *Paul's Place* suggest, in their own ways, that consumers, and parents of consumers,

need to be heard and respected as individuals. And they serve as a reminder that what works for one consumer doesn't necessarily work for another.

We are pleased to have received two articles for *Readers Write*, one from South Africa, and one from Canada. Thanks Faizah for a very informative article. Your problem is shared more widely than you think. Thanks also to you Paul Sullivan for sharing your article that won the travel scholarship to attend the ISAAC conference in Maastricht, The Netherlands, being held this October. Congratulations Paul and best of luck in Europe!

The only column I haven't talked about is *SymbolTalk*, or *ShirleyTalk*, as we are calling it for this issue. I'm not going to say much about it except that I urge everyone to read it. Shirley talks from the heart about professionalism. Those of you who know Shirley, know she is a giver. I have called her at various hours of the day or night and she has always been willing to help out; whether it's making a few phone calls for me or just giving me advice or reassurance. Thanks, Shirley for being the person you are and thanks for sharing such intimate thoughts.

As you read this issue, it will be easy to see that each professional / consumer relationship is unique. I feel the most important factor in any relationship is respect. Hopefully, when there is respect everyone can work together rather than against each other.

Be watching for the following themes in upcoming issues: September 1994, Aging; December 1994, Welcoming Environments; March 1995, Developing My Own Voice. If you have articles you want to share with us, please write.

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Sheila

ROB HAAF, NOLA MILLIN,
GEB VERBURG

During our annual editorial meeting this past March, when the themes for the next year's issues were selected, we debated how a feature article could best illustrate the theme of the Professional-Consumer Relationship. We decided to present an example of such a relationship, to highlight some of the most desirable features of a good working partnership between a client, the client's family and the clinical team. After some discussion, it was decided to focus on the situation of Sheila.

Sheila is a sixteen-year-old girl with cerebral palsy, who lives at home with her family. She attends her local school where she is enrolled in a regular grade ten class, with the assistance of a part-time classroom aide and daily resource support. She receives all of her therapy and consultation services through a local rehabilitation centre. Although physiotherapy and occupational therapy visits take place at school, therapists are based at the rehabilitation centre. The consultative services she requires at this point are primarily seating, mobility and augmentative communication. Sheila drives a power wheelchair and uses a Touch Talker™ mounted on her wheelchair, along with a word/spelling board which is integrated with her wheelchair tray. She also uses a computer for written work at home and school, which is accessed through her Touch Talker™.

Sheila and her family have been involved with this centre for a number of years, though the profes-

sional team has changed frequently. It's important to point out that the relationship described is one that has evolved over time. When they were first beginning to deal with professionals and the entire service delivery system, this young girl and her family could not have reasonably been expected to be totally knowledgeable and aware of all of the options available to them. While they needed to be active, vocal members of the treatment team from the outset, Sheila and her family also needed the time and experience to become comfortable in dealing with the various professionals. They

The various professionals involved in service provision recognize that they are there to act as resources to Sheila and to her family, not as "experts to be listened to".

needed to become aware of what each individual could and could not do for them. They also needed to become familiar with the sometimes bewildering and often frustrating routines involved in interacting with medical professionals. Over time, Sheila and her family recognized that they were the most stable members of the team. As such, they had to be the ones who ensured that the overall focus was not lost when individual team members departed and were replaced.

When Sheila was younger, she was less able to advocate for herself and so her parents assumed this role. As a young adult, Sheila is involved in all decisions about her care, and her parents have let her take the

primary role. She is "militant" in her self-advocacy, frequently calling team members, asking questions and calling meetings to discuss important issues. This attitude on the part of a consumer helps to ensure that needs are met as quickly as possible. For the most part, clinicians see an aware, active consumer as someone who is most likely to follow through with recommendations, and so are willing to make an extra effort on her behalf whenever necessary.

Overall, the attitudes held by each participant in this relationship are those that seem to be most conducive to a good working partnership. Sheila and her family see their role as ensuring that her needs remain primary in all decision-making. They are the "experts" when it comes to Sheila's abilities and needs. The various professionals involved in service provision recognize that they are there to act as resources to Sheila and to her family, not as "experts to be listened to". At their best, the professionals at the rehabilitation centre provide information as to all of the options available (not just those that the clinicians think are "best") and provide training and follow-up support when the final decision is made. The concerns and input of the other professionals and caregivers (including teachers and classroom aides) are encouraged, and actively sought out in all decision-making. Thus, Sheila's team consists of all those individuals who have a stake, personal or professional, in the decisions being made. Most importantly, while the roles of each participant must be and should be quite distinct, the status of each team member is equal.

Of course, with so many people involved in decisions that are in many cases important and far-reaching, total harmony and the absence of conflict is unrealistic. When one participant perceives that a mistake has been made on the part of the other, the strengths of the relationship become apparent. Sheila and her family assume that delays, games of "phone tag", etc., are due to the pressures of caseloads and the tyranny of policies and procedures, not to an inconsiderate, uncaring professional. Similarly, the professionals involved recognize that the realities of day-to-day life for a child with a disability can sometimes prevent Sheila or her parents from immediately following through on tasks.

When Sheila or her parents have disagreements with the professionals on their team over the course of intervention or about priorities. They are for the most part, however, able to talk to the person(s) involved about their concerns and arrive at a suitable compromise. This wasn't always the case. Both Sheila and her mother report being incredibly frustrated when they felt they couldn't voice opinions that were contrary to the "experts". Their only course of action was to passively resist the suggestions they disagreed with, leading to a perception that they were "negative", or "unwilling to accept the realities of the situation". When they had finally established a relationship with clinicians that allowed them to voice their opinions and work out a compromise, the difference in their feeling of empowerment and subsequent commitment to agreed-upon goals was considerable. This boiled down to a sense of trust among everyone involved, a critical realization that everyone was trying to work towards a common goal of advancing

and developing Sheila's abilities. Most often, the frustrations over the availability of funding, technical problems, etc., that Sheila was experiencing were shared, and not caused by, the professionals on her team.

Sheila now recognizes that, as resources, the professionals on her team are obligated to provide information on specific devices, interventions, other services, etc., when requested. Sheila is not afraid to ask clinicians on her team for information about, or to see, a specific device or aid, even if the clinicians on her team may not recommend the device, or perhaps feel that it is not the most appropriate option for her. For example, recently Sheila expressed a desire to try a standard keyboard with a keyguard on her computer at school. While clinicians on her team expressed their opinion

Most importantly, while the roles of each participant must be and should be quite distinct, the status of each team member is equal.

that this was not as functional a solution for her as using her Touch Talker™, the clinicians recognized that Sheila needed to try it for herself and make her own decision. The consequence of this level of responsibility is that while the decision is ultimately Sheila's, she needs to assume responsibility for the decisions that are made, even if they turn out to be wrong.

When clinicians meet with Sheila and her family, they talk to Sheila, not to her family or teachers. When written reports, letters, etc., are sent, they are routinely mailed to Sheila directly, who keeps copies of

her own records. No report or other written information is sent out to any agency without the written consent of both Sheila and her family. Following every meeting, Sheila, with the assistance of her mother, writes a summary of the meeting and the decisions reached. This heightens Sheila's perceptions of the meeting and its outcome, and includes a listing of the responsibilities of each team member resulting from the decisions reached in the meeting. Sheila's summary is shared with everyone involved with her care. This way, everyone has the opportunity to correct misunderstandings about steps to be taken, who is to take them and when. Everyone recognizes that the majority of problems that can occur stem from miscommunication and misunderstanding; all of the steps taken to minimize this are worth the extra effort involved.

While it is not logistically possible for every team member to be present for every meeting, the various professional teams and team members at the treatment centre and in the community actively strive to maintain a good working idea of what everyone else is doing, and team members meet regularly to update each other. So, for example, the seating and mobility team met with Sheila to discuss modifications to her existing wheelchair tray (she wanted a smaller, less cumbersome tray). While clinicians from the augmentative communication team couldn't attend, it was recognized that any changes to the tray would mean modifications to her communication display, and so any final decision was deferred until seating personnel (and Sheila) could meet with augmentative clinicians to explore all issues. Similarly, school personnel were involved with the

final decisions, as any new tray would have to accommodate a variety of academic activities. The common denominator for almost all meetings is, not surprisingly, Sheila and her parents.

Sheila and her family are involved and the final decision is always Sheila's. In this way, she is respected as a person in her own right. When decisions are being made regarding assistive technology, Sheila's opinions and ideas are listened to, and *her* needs (not the preferences of the professional team or convenience of family member or school staff) are paramount. A good example is when Sheila had an idea about how to mount her Touch Talker™ on her wheelchair to allow her to more easily stabilize herself to access the device. She demonstrated her idea to her augmentative communication clinicians and to the seating technician during a clinic visit, and her ideas ended up as part of the final design.

Wherever possible, professionals accommodate Sheila's needs by setting appointment times that are workable, given transportation schedules and difficulties. At the same time, Sheila is sensitive to the difficulties of a busy schedule. A good compromise was reached with Sheila's augmentative communication consultants by having Sheila come to the clinic to see them on one occasion, and the clinicians coming to Sheila's home the next time, and so on. Of course the specifics of the problem have to take precedence: making modifications to a wheelchair insert is difficult to do anywhere but in a seating clinic. But a clinic visit isn't much good when Sheila's home computer breaks down!

While the great majority of professionals that Sheila has encountered are supportive and willing to work towards mutually defined goals, on occasion a professional has been assigned to the team who has difficulty accepting the degree of control that Sheila and her family insist upon. It is often newly graduated clinicians who have some difficulty initially. Working within a collaborative, consultative model is something that is not often taught in the health professions. When this occurs, Sheila and her family have found that it is not productive to immediately confront the individual and try to make him or her "see the light". Often, some time working within an established team will help an individual recognize the wealth of experience and knowledge everyone brings to the collaboration. If not, it's good to remember who has hired whom.

* * *

After reading this description of a professional-consumer relationship, we would guess that readers will have various reactions, ranging from "How can I make this happen for me/my child?" to "So what's new? We do this every day." Okay, then, now for our confession: When we were discussing the features of an ideal relationship last March, we were able to come up with many points that we felt were necessary for successful consumer-professional collaboration. However, when we tried to identify an actual partnership that exemplified all of these features, we couldn't! So, we decided to present our ideal features in the above format. Many details were taken from existing clinical relationships and actual events, and expanded on with the help of discus-

sion with parents of "real life" consumers. Nevertheless, all of the features presented couldn't be found within the experience of any one team of an individual.

We felt that this approach served to highlight the fact that all of the ideal aspects are extremely difficult to achieve in the real world. Often, the service delivery system itself works against establishing all of the ideas that we have presented in this article. It is important to realize that even in the best working relationships that we can identify, there is more than enough room for growth.

We hope that regardless of your role on a collaborative team, you have recognized some aspects of the relationships within Sheila's program as being similar to your working relationships with professionals or consumers. Perhaps, in fact, many of the ideal features we've presented typify your working relationship. If so, you are to be congratulated; it's not as easy to develop as you may think. Rather than rest on any laurels, however, we would strongly urge you to think of ways to share your experiences and strategies with other parents, consumers and professionals. Join parent support groups. Hold workshops. Write an article or a "Yuck" or "Wow" for **Communicating Together!** Do whatever it takes to spread your knowledge to all who need it. For those of you who are experiencing a less-than-ideal working relationship, take heart and keep striving for change. Remember that the importance of the decisions being made demands that you work towards the best consumer-professional relationship possible.

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Yucks & Wows!

NOLA MILLIN

It is my pleasure to introduce a brand new column! *Yucks & Wows* was created at our Annual Editors' Meeting in March. You would be amazed to see what goes on during our annual weekend together! Anyway, this column is unique. It will be whatever the readers want it to be — anything from completely off-the-wall to totally serious, or anywhere in-between. That's right, I'm looking for input from you, whoever you are!

The intent of this column is to have tid-bits of everyday life. *Yucks & Wows* is for everyone and anyone. If you are an AAC user, a parent, a professional, or a next door neighbour, you have something to contribute! You can write about something good or humorous that has happened to you or someone you know. Or you can write about something bad or something "ugly". We have all had experiences that are worth sharing. Don't tell me I'm the only one who has an electric wheelchair that decides to break down when I'm sitting outside in the middle of a

downpour! Am I the only one whose word board has been left on top of the car roof only to be discovered when we have gotten to the destination? I'm sure I'm not. I know other people must have these unique experiences. Have you as an AAC user, or a professional, waited for a piece of equipment for months and months, only to have it arrive broken? Please tell me you have. Anyway, if you're willing to share these good "Wow" or bad "Yucky" experiences, I want to hear from you.

I see this column as being a great opportunity for people. A lot of folks get frightened at the idea of writing an entire article *but* they have things to share. This is where *Yucks & Wows* can help out. You don't have to write an article. You can write a sentence or two, or a paragraph. If you are inclined to write an entire article that would be great; we are always open to articles! I'm willing to accept anything; poetry, cartoons, one liners or even wishes. Have you ever thought to yourself, "I wish someone would invent ..."? Well, write your idea down. We have

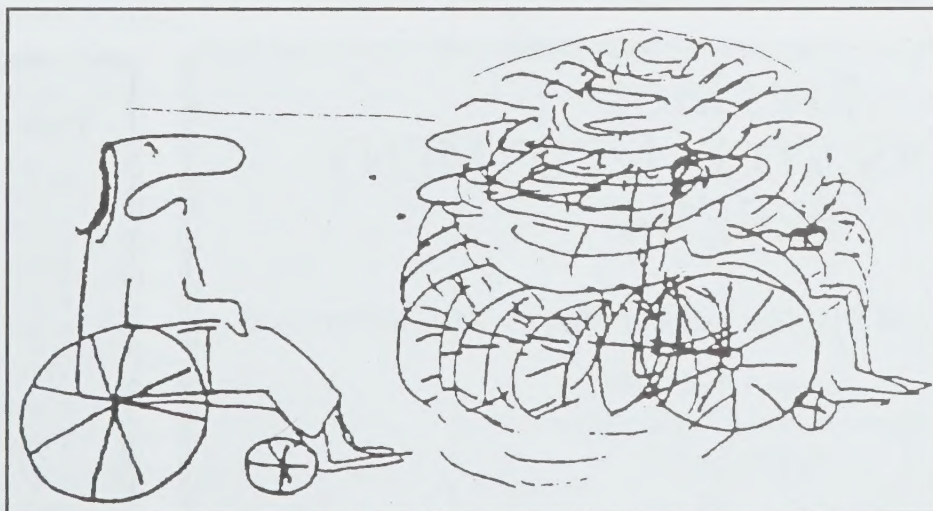
researchers who read **Communicating Together** so who knows, your idea might result in an invention.

The only stipulation I ask, is if you use someone else's material that you get permission and you quote the source. If the source is unknown, then we will say so. We just don't want any legal suits on our hands! I, also, see this column as being controversial at times. If I get some controversial subject, I will try to obtain the opposing view and print both sides.

For this first column, I thought I would share a cartoon that I can relate to and include a short article submitted by Jean Blancher expressing a *Yuck* re telephone communication.

Since I have had the cartoon for years, I don't have a clue where it came from. (If the cartoonist is reading this issue, I apologize for not asking your permission to use it.) Doesn't this cartoon summarize how some service delivery people think? They don't seem to understand that we have to be innovative!

Yuck #1



**"That is probably hard on the steering device.
Can't you just stir your coffee?"**

Yuck #2

Just Call . . . Eh?

JEAN BLANCHER

From the time I learned to talk I have had no illusions about being immediately or readily understood. Nevertheless, I am stubborn enough to try communicating as occasions dictate. The trick is to persevere and hope that my listeners will do the same. Often, this tactic works. But when it doesn't, I find myself in the darndest situations.

One such situation arose a few weeks ago when I called Consumers Saving Club, a grocery delivery service, for information. The woman who answered was patient but obviously flustered by my unusual speech. Finally, she hung up after approximately ten minutes without realizing that I was simply asking if the business had a FAX number.

Still determined, I immediately called back. That time, I reached a man who sounded equally perplexed. Thus, I changed my approach and asked him to send me a catalogue. I hoped that by giving my name, address and telephone number I would establish credibility and a

rapport with him. My efforts were to no avail. Although he caught the address, the rest apparently evaded him for he repeatedly kept asking, "Are you in trouble?" I frantically responded, "No, no, no!" Nevertheless, he convinced himself that I was in distress and, before he too hung up, he insisted that he would call the police for me. At that point, I acquiesced to asking the woman who provides our home help to call to explain our circumstance and obtain the desired information.

The man, however, had already kept his promise. Within a few minutes two police officers pounded at the door and entered, followed by two ambulance attendants, and Angel. One of officers asked what the trouble was, to which I assertively replied "Nothing!" He then wanted to know if I had called them. I assured him that someone else had - I had *not*. Meanwhile, Lew, my husband, was in the den turning purple with anger while an ambulance attendant investigated the rest of the apartment. Our visitors

departed after finding nothing amiss, leaving us to ponder the events.

I can empathize with the feelings of frustration, fear and inadequacy that the individuals taking my call experienced. I also appreciate the concern of the man for my welfare and his taking what he thought was appropriate action. However, when I and any other prospective customers with the linguistic phenomenon cerebral palsied playwright, David Freeman, termed a "C.P. accent" call, hopefully the person at the other end of the line will be prepared. We only want what we need delivered.

*I hope I will hear from our readers with more "Yucks & Wows". You can write: Nola Millin, at **Communicating Together**; Box 986, Thornhill, Ont. L3T 4A5 or Fax me at 519-735-4443, or E-mail me at: "rtrdcnm@oise.on.ca".*

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What an Unlikely Couple! The Marriage of Semantic Compaction and Word Prediction

JEFFERY HIGGINBOTHAM



From Robert Haaf, Associate Editor:

For this issue, we are pleased to welcome Jeffery Higginbotham back to the pages of "Consuming Technology". Jeffery is on the faculty in the Department of Communication Disorders and Sciences at the State University of New York at Buffalo. He offers an exciting and thoughtful insight into a future direction of communication technology and the advantages such developments could offer to users of augmentative communication systems. His article has made me think carefully about the development of communication systems, thoughts I hope to share in more detail next issue. I hope it will do the same for you.

One of the truisms that I have learned during my life is that those things traditionally viewed as being opposed to one another, at some point in time begin to assume the characteristics of their competitor (e.g., U. S. Democratic Party becoming more conservative) or combine to form a new, more powerful entity (e.g., the Apple - IBM alliance). In the Augmentative

& Alternative Communication (AAC) field a similar situation is occurring with respect to semantic compaction and word prediction systems. Because of differences in their appearance and operating requirements, they are frequently regarded as representing opposing approaches to AAC communication. Instead of viewing these systems only as competitors, I would like to discuss a way by which semantic compaction and word prediction can be combined into a single, more powerful AAC system providing the user with complete vocabulary access for speaking or writing.

Semantic Compaction Systems

Semantic compaction is a concept introduced by Bruce Baker in the early 1980's, describing a process of associating meaningful concepts with vocabulary items using pictures or icons placed on a keyboard.

it the name "Minspeak". In contrast to traditional orthography (e.g., the English alphabet), the semantic compaction system allows the communicator access to vocabulary (words, phrases and sentences) through the selection of one or more icons which represent the vocabulary item. For example, the Words Strategy™¹ system represents the concept of "thinking" by using the 'idea' icon.



A number of related words can be formed by associating the 'idea' icon with other icons and grammatical tags (see chart below).

Proponents of semantic compaction note that the conceptual richness of this graphic-based approach permits large numbers of meaningful associations to be made with a restricted symbol set and that

Vocabulary Item	Icon(s)	Grammar Label
idea →	 Idea	+ Noun
think →	 Idea	+ Verb
thought →	 Idea	+ Verb-ed
awake →	 Idea	+ Adj
believe →	 Idea	+  + Verb
imagine →	 Idea	+  + Verb

these associations can be organized using knowledge already available to the user and/or his community (e.g., semantic categories, personal experiences, English grammar, American Sign Language). Vocabulary sizes for current semantic compaction systems range from a few hundred to several thousand words ².

When evaluating the efficiency of the MinspeakTM-based semantic compaction system Words StrategyTM ³ (Higginbotham, 1992), we found the overall keystroke savings to be about 36%. This was about 10% lower than the word prediction systems it was compared to. This difference in keystroke savings was due primarily to the keystrokes spent switching between icon sequencing and spelling modes ⁴. A 60% keystroke savings was found for the words accessed from the pre-stored Words StrategyTM vocabulary, however, which was more efficient than any of the other technologies evaluated. Thus, semantic compaction can provide a highly efficient means of vocabulary access. Ways need to be developed, however, to circumvent mode-switching and the need to spell out novel words.

To date, designers have been able to extend the Words StrategyTM vocabulary to over 4000 words, as well as circumvent the need to manually shift between spelling and icon sequencing through the use of the new AutospellTM technology incorporated into the Prentke-Romich LiberatorTM system. These changes have improved keystroke savings to at least 45%, which is commensurate with current prediction technologies. To approach the 60% efficiency levels achieved using a pre-stored vocabulary, however, designers will have to develop a pre-stored vocabulary of at least 10,000 words, with each word being associated with a distinct icon sequence.

Even with the ingenious techniques employed by designers thus far, it may not be possible to access a vocabulary that size via semantic compaction alone. The solution to this problem lies with semantic compaction's arch-rival, word prediction.

Word Prediction

Word prediction, as I have described more fully in previous issues of *Communicating Together* ⁵, is a technique used with microcomputers to facilitate text composition by providing the user with several likely choices for the word being typed. Typically, the word prediction program presents a list of five to ten words on the screen as the user is typing text. If a word in the prediction list matches the word that is being typed out, the user can select that word (e.g., type a number associated with the word) and the entire word will be typed out automatically. If the entire word isn't available on the prediction list, the user continues to type until it becomes available or is spelled out.

The efficiency of word prediction systems is dependent on the ways in which words are selected by the computer to appear on the prediction list (Higginbotham, 1992; Higginbotham et al, 1992). Keystroke savings for prediction systems developed for AAC use generally range between 35% and 50%. However, in order to achieve such efficiency, most prediction programs require the user to search the prediction list on the computer screen after each letter typed. The constant need to monitor the screen for word predictions can be detrimental to the writing process by increasing fatigue, forgetting and confusion, as well as slowing down overall typing speed.

Combining Semantic Compaction with Word Prediction

As can be seen from the above

discussion, semantic compaction and word prediction present radically different approaches to accelerating communication and providing vocabulary coverage. Each system also possesses its own strengths and weaknesses. However, I think that there is real merit in exploring ways to combine the strengths of these two techniques into a single 'hybrid' communication system.

One way would be to employ a semantic compaction strategy to access a user's base vocabulary, and apply word prediction to deal with infrequently used words and new word acquisition. For example, using Words StrategyTM ⁶ a communicator could potentially access 90% of her vocabulary via semantic compaction. Here the user accesses the word "dress" with 2 keystrokes:

$$\text{dressing} \rightarrow \overset{D}{\text{Icon}} + \text{verb-ing}$$

However, if the user wanted to retrieve the word "dictator", which isn't in the Words StrategyTM vocabulary, she would begin typing:

$$\text{dictator} \rightarrow \overset{D}{\text{Icon}} + \overset{I}{\text{Icon}}$$

Because no word in the base dictionary is associated with the above icon sequence, the communication device would switch automatically from an icon sequencing mode to a spelling/word prediction mode ⁷. Now the predictor would begin to display a list of 6 or so words on the device's display screen. If "dictator" was displayed in the word list, the user could select it by typing in its associated number. If the word wasn't predicted, the user would continue to spell out the word until it appeared in the word prediction list or was spelled out.

Employing the current 4000-word Words StrategyTM vocabulary, the user would be able to access about

90% of her vocabulary via semantic compaction. The other 10% of her vocabulary needs could be met by prediction. Without actual implementation of this technology, it is not possible to provide hard data on the keystroke savings. Based on previous research data with similar systems however, (Higginbotham, 1992), a keystroke savings of approximately 65% may be achieved using the hybrid semantic compaction/prediction system. Similar strategies could be employed to enhance other semantic/graphic based systems.

Conclusion

I think that the old adage "opposites attract" is particularly pertinent for the future relationship of semantic compaction and word prediction systems. In this article I have briefly described just one of the ways in which these two approaches could be combined to benefit an individual's communication. Other applications could provide the user with on-line vocabulary assistance, dictionaries

and other features. Such advancements will certainly come about as clinicians, developers and researchers consider how various technologies might be combined to assist the consumer.

Notes

1. Although Words Strategy™ is used to illustrate the semantic compaction concepts in this paper, other systems could potentially utilize the same techniques.
2. The current implementation of Words Strategy™ on the PRC Liberator™ contains approximately 4,000 words and phrases in its vocabulary.
3. Keystroke savings estimates were based on a 2,500 word vocabulary used by the PRC Touch Talker™. Written transcripts obtained from twenty able-bodied individuals across four grade levels were used for the analysis.
4. The disparity in keystroke savings has been subsequently eliminated with the introduction of the Autospell™ technology by PRC.

5. Please refer to *Communicating Together*, volume 10, nos. 1 and 2 for much more detailed descriptions and comparative evaluations of word prediction systems.
6. This approach is currently being considered by the Prentke Romich Company for their Liberator™ communication aid.
7. Automatic transition between icon sequencing and spelling modes is accomplished using the Autospell™ technique.

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Parents' and Consumers' Views of Professionals

PETER LINDSAY

The theme for the June issue – consumer/professional relations – arose in part because of my experience teaching a graduate course on Empowerment and Disability for students in Special Education at the University of Toronto. The course explores the human side of disability using a “case study” approach. Many of the case studies have been so insightful that we have published them in a volume entitled **Empowerment and Disability: A Book of Human Stories** available from Sharing to Learn.

Over the years as these stories have unfolded, it has become increasingly apparent that the professional-parent relationship plays a central role in either empowering or disempowering both the parent and the individual with the disability. In their constant struggle to support and advocate for their children, parents have horror stories as well as stories of great humanity to tell about their interactions with professionals. Usually the encounter with professionals starts at the very beginning, influenced by the way the parents are treated by the medical staff when they discover that their new baby “has something wrong with it”. They may sense something is wrong because of subtle cues – the furtive look by a nurse, the nurse who seems to avoid their room, or the delay in bringing their baby to be fed. When they leave the hospital, their interaction with professionals carries on as various “allied health professionals”

appear on the scene – the speech pathologist to help them find a way to communicate with their child; the occupational therapist to help with seating and mobility. The professional interactions continue right on into the school years where parents usually come face to face with vigorous debates about the appropriateness of inclusion and integration and whether their child should really be taught with the others. Parents must somehow deal with bureaucratic wrangles as to which government ministry is responsible for what support. All this ends quite abruptly when the child reaches adulthood. Usually at the age of 21 all services and hence resources for professional support is reduced drastically.

Some parents seem to be empowered by the process. They say that the journey is difficult and frustrating but at the same time it can be exhilarating and very empowering. Others, on the other hand, seem to be totally defeated by the process. What makes the difference? We wanted to hear parents' and consumers' stories about their relationships with professionals — what made them good and what made them bad. We began with a set of questions to serve as memory prompts.

In this issue we are including the reactions from the first respondents. We're starting close to home and hearing from Rosemary and Paul Marshall and from five AAC users — John Dowling, Darlene Gallant, Susan Odell, Ann Running, Aaron Shelbourne — and their instructor, Sherry Parkins, in a North York Board of Education Adult Literacy Program.

I have listed each of the questions in a box. Each question is followed first by Rosemary's response then by

the responses of Sherri's students. We are still interviewing parents and AAC users. Their stories will appear in future issues of **Communicating Together**. We also invite any of you to respond to the questions and/or write about your experiences.

1. Overall, have your contacts with professionals tended to be positive or negative?

Rosemary:

Overall, our dealings with professionals tended to be positive. With us, our dealings haven't been over life and death circumstances, therefore we have been able to weigh the factors over time.

AAC Users:

We feel that interactions with professionals have been both positive and negative. One of us feels that her experiences have been predominately positive.

2. Please describe your most positive experience with a professional.

Rosemary:

I can't think of just one experience that really comes to mind. My positive experience with professionals happens whenever they see Paul as a person first and then as a person with a handicap. The trick I feel is to go into any situation without setting your expectations too high. You don't have to have control over some relationships; sometimes it is how you present yourself.

AAC Users:

One of us has had a very positive association with a medical professional over many years. This individual has taken the time to learn to interact effectively with her as she uses her augmentative communication system.

Listening is a vital component of whether or not the interaction is positive. Professionals who know that talking

with an individual who uses augmentative communication takes time, and gives them that time, contributes to a positive experience.

Teachers who have provided and taught a way of communicating effectively have left a lifetime impact on several of us who use augmentative communication.

Professionals who never give up on seeking ways to increase independence have left lasting impressions. Levels of independence never would have been reached without their professional perseverance.

One person commented that police have generally provided positive experiences.

3. Please describe your most negative experience with a professional.

Rosemary:

There are a few of them. First when Paul was born, the doctors were extremely negative about his future. Things like: "You will have to wake him up for feedings" and "Your son will never do this or that". It was a few years before we learned that Paul had cerebral palsy since they didn't name the problem.

Second, in order to learn Bliss at age 12, Paul had to go back and spend a school year at the C.P. centre where we had moved from into a normal school with three classes for the handicapped. The red tape from the school board to get Paul back there was unbelievable. We told the professionals involved, "Give him a week, then we will know." They wrote that off. To make a long story short, the first day Paul came home from Barb Rush's communication class, the whole family knew that Bliss was Paul's communication breakthrough.

The third example of a negative experience with professionals involved a work placement assessment. As Paul describes it: "On the first day, they put me at turning over a garden. It was a very hot day that broke the records for heat, plus they didn't tell me what I would be doing so I was without work gloves. By

the end of the day my hands were a mess, but I was bound to stick to it. I was dehydrated and the family doctor said close to heat stroke. It was like they didn't know what to do with me so they put me at that job to get me out of the way."

AAC Users:

Negative experiences have often occurred within the medical profession. Some of us remember being hit by nurses who were caring for us. Some nurses treat nonspeaking persons as though they are mentally handicapped and incapable of directing any of their care.

A teacher who ignored and didn't treat one individual as a person with the ability to learn resulted in the student losing her trust in teachers for a time.

Generally, government people also win an award for being the worst at interacting with people with speech impediments. They are very impersonal and their responses tend to be very slow. We are never sure what the rules are from one day to the next!

Transit system drivers can sometimes be insensitive with the comments that they are making. They may feel that they are having fun but the comments are not always appropriate or welcome.

4. Based on your own experience, what advice would you give to other parents about the best way to get useful professional help?

Rosemary:

I think the most valuable message that I could give to other parents is to never lose hope, dreams and desires to improve the quality of life of their children. This will be their motivation to seek and keep on seeking useful professional help through parents' groups, self-help groups, doctors, therapists, etc. Sometime as individuals, we have to learn to walk alone to get to where we need to go.

AAC Users:

Some of the advice we would give to others seeking professional assistance is

to assert yourself. Don't give up! Be persistent! *Be a Pain!*

5. What do you think are the most important responsibilities of the parent in the parent-professional relationship? What are the most important responsibilities of the professional?

Rosemary:

On the parent's part: A. Listen to their input with a totally open mind. B. Do not prejudge on past parent-professional relationships.

On the professional part: A. Each case has to be worked through on an individual basis. B. Work on the positives and not the negatives. C. Never use the words "can't" or "will not". D. Motivate parents even if you have to use strong wording.

AAC Users:

Advice to consumers:

Be prepared. Know what you want, need or are trying to say. You need to be patient with people as they learn how you communicate. It is your responsibility to ask questions to get the information you want and need. Make sure that an appropriate amount of time has been allotted to deal with the increased time requirements for communication.

Advice to professionals:

Take the time that augmentative communicators need. Come down to a level so that AAC users can benefit from your teaching, but, don't insult their intelligence.

Professionals need to be able to accurately assess the abilities of persons so that they can appropriately provide services.

Some of the best professional help has come from informal professional interactions. Friendships have often been the result of long term professional involvement. Occupational therapists have often provided effective professional assistance.

Most of us appreciate the investment of time to interact with us. Don't be afraid to have a sense of humour but not at our expense.

6. *Who usually made the final decision with regard to the programs or help your child needed?*

Paul jumped in to exclaim: ME!!

AAC Users:

In the past, parents, caregivers or professionals made decisions for us. Now we feel that we are able to direct more of our own decisions. We appreciate professional input but we like to make the final decision ourselves. Sometimes part of the process includes debating the issues involved.

7. *How would you describe an ideal professional from the parent's or consumer's point of view?*

Rosemary:

Those who have compassion for their work and for their clients. They can deal with their cases on an individual basis. They aren't afraid to go out on a limb and say what needs to be said to motivate their clients.

AAC Users:

An ideal professional would take the time to listen, be skillful in their profession, understand disabilities and their issues, and have a warm personality.

8. *How could the kinds of training professionals receive be improved?*

Rosemary:

I feel there should be a section in the training of all professionals that helps them to get a feel of what their clients go through in their lives. Example: have a student go without talking for a few days or sit in a wheelchair for a few days.

AAC Users:

Training must include communication strategies and teaching on how to interact with persons using augmentative communication. Consumers should be involved in the development and in the actual training of professionals.

9. *Do you see the "system" as generally supporting effective relations between parents and professionals?*

Rosemary:

It is hard to say. Generally the "system" works on the outer shell but it is when you do some digging, you find where the "system" has failed. Parents have their own mandate and what I am finding is a large number of them are unreasonable. Even if the professionals could work "wonders" to fix everything, the demands would never stop. I think the underlying issue is one of acceptance of the handicap. I feel when you accept your circumstance then you can move on to making changes in your world and the world around you. Generally the "system" is getting much better I feel.

AAC Users:

Generally the "system" has only changed a bit in regards to establishing positive professional relationships. Sometimes the left hand does not know what the right hand is doing. There needs to be a more concerted effort to work together!

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TEACHING AND LEARNING

Show and Tell

SMITA WORAH &
MADHAVI TAMBAY

The teacher-student relationship is unique. There are more opportunities for them to mesh roles than is typical in most professional relationships. Who is the teacher and who is the student? The teacher may create the opportunity for instruction and communication but the student must go on from there.

We were very pleased to receive this description of a learning situation written by a teacher and a speech pathologist in Calcutta. It could easily have been placed in the "SymbolTalk" section as part of our ongoing study of graphics and language development. With Smita Worah and Madhavi Tambay it is happening!

It was Tuesday morning, Deepak came in looking excited and happy. Deepak had brought his favourite toy to show to his friends. But he knew he had to wait for "Show & Tell Time". With great difficulty, he controlled his excitement. As soon as it was 10:30 a.m. and time for "Show & Tell", he requested me to take "the toy" out of his bag. And what was it? It was his precious toy aeroplane! He certainly had a lot to tell us about it.

Deepak is one from a group of six cerebral palsied children in the age range of six to nine years, whom I teach. Five of them are non-speaking with extremely limited functional speech. The sixth child, Sujit, has severe dysarthric speech. All the five non-speaking children use a combi-

nation of picture-Blissymbols and word communication boards for "speaking" and have been on an augmentative and alternative communication system (AAC) for at least three years.

Deepak, Sajjidul, Shivjyoti, Sameer, Tabassum and Sujit follow the kindergarten syllabus. All of them, I feel, understand a lot more than what they can express, and I have been concerned with narrowing the gap between the children's receptive and expressive abilities. Madhavi, our speech therapist and I felt that the AAC users needed opportunities to initiate conversations, talk about their interests, and be in control of the topics of conversation. Usually in a classroom

All of them, I feel, understand a lot more than what they can express, and I have been concerned with narrowing the gap between the children's receptive and expressive abilities.

situation, the teacher tends to give a lot of input that can be processed by the children receptively. But the teacher may not be able to provide an adequate number of opportunities for generalized use of language. With non-speaking children this is a major area of concern.

Madhavi was also concerned with encouraging the children to choose the topics of conversation, improve their interaction skills, learn to ask questions along with using the limited vocabulary available to them

in a creative and functional manner.

Coming back to the "Show and Tell" class, as I put the aeroplane in front of Deepak and his friends, he pointed to his board "Mother, shop, yesterday, buy, I, sister play home aeroplane." Before Deepak could finish, all the others were trying to put their own bit in. Eye pointing (indicating 'this') to the aeroplane Sameer said "Aeroplane small". Sajjidul contributed saying "Aeroplane sky fly". Examining the aeroplane Sujit added verbally, "It has one door and many windows". Shivjyoti answered the teacher's question "Who flies an aeroplane?" by pointing to the word "Pilot". Tabassum was peering inside the aeroplane and I prompted her "Do you want to ask something?"

Tabassum, taking the cue, pointed to the symbols of 'question' and 'inside' meaning "Who is inside?". The conversation continued freely for the next twenty minutes or so. The topic was chosen by them and there was a lot of interaction amongst them. They used the symbols on their communication boards, gestures, eye pointing and some speech to interact. I sat back, helping only when necessary, e.g. verbalizing messages given on communication boards.

In the language class, I had introduced the children to the articles 'a' and 'an' and their use. We were also learning singular and plural words. The "Show and Tell" class gave me an opportunity to revise their concepts once again. I wrote on the black board "A pilot flies an aeroplane. This aeroplane has one

door, but many windows.” The language structures were emphasized in meaningful context. My homework that day included filling in the blanks with articles ‘a’ and ‘an’. Needless to say all of them did it correctly. I also introduced the word/symbol “airport” — place from where the plane takes off or lands. Madhavi, the speech therapist, suggested we use the symbol ‘fly’ for take off and the opposite fly for landing. The children used three to four symbols spontaneously. Language teaching, communicative interaction and fun were all integrated.

Working with a group of five to six non-speaking severely physically handicapped children throws many challenges to the teacher. Some of them take a very long time to give their message and even then access may not be accurate. The more able ones start answering in between and the teacher is at a loss where to give her attention. The children in my class are at different expressive levels. Shivjyoti who is severely

The teacher may not be able to provide an adequate number of opportunities for generalized use of language. With non-speaking children this is a major area of concern.

physically disabled is capable of giving long three to four symbol phrases, given the time. But Tabassum who is more able gives only two symbol phrases. Deepak and Sajjidul cut in repeatedly with their single word speech.

Over the next few weeks, the show and tell class was a big success. The children actually were after their moms to give toys to bring to school. Thus we had our ‘chatting’ sessions about a doll, tea set, coloured felt pens, cricket bat & ball in cricket season and, believe me, a pump used to spray mosquito repellent!

Let me narrate another interesting episode. Once Sajjidul came with a sponge and two bottles of paint. He told me it was used for painting and went on to instruct me to get paper, water and brushes. Others agreed readily as they all enjoyed painting. As the class progressed and conversation flowed I introduced the concept of soft sponge and hard table. The sweater which Sameer wore was also soft, I pointed out. But the chair was hard. We spoke more about different hard and soft objects and these symbols were introduced on their communication boards. When they finished painting, the sponge was put in a bowl with a little water. The children experienced that the ‘light and dry’ sponge became ‘heavy and wet’, as the water went ‘inside’ the sponge. All kids were in turn given an opportunity to ‘press’ the sponge and bring water out. The little game of pressing the sponge to squeeze out the water delighted all of them tremendously. Deepak surprised us all by pointing out that the sponge had become clean, but the water was dirty. Hearing this it was my turn to be delighted!

All through the game of show and tell the kids had made a painting each and many new vocabulary items were introduced as new concepts were learned. The children ex-

pressed themselves in two to four symbol phrases using adjectives, nouns and verbs. And we all had a great time!

Language teaching, communicative interaction and fun were all integrated.

The second stage of this game is “Hide and Tell”. The child who brings an object of his interest will first give clues to his friends and they will guess what the object is. This will involve parents as well, for they may have to teach their child how to give subtle clues. Often they may have to introduce the relevant vocabulary before the child comes to school.

In India the schooling system places a lot of emphasis on examinations. The cognitively able but severely physically handicapped non-speaking children also follow the normal school curriculum. This places great demands on children as well as the teacher and the therapists. Incorporating physical therapy and speech communication goals within academic goals is a difficult task. We felt during the Show & Tell class we had taken a step forward in that

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Editor's Note

Ms. Smita Worah is a special educator at the Centre for Special Education, Spastics Society of Eastern India, Calcutta. Mrs. Madhavi Tambay is a senior speech therapist at the same centre. Their excellent description of primary language learning in an Indian classroom is a strong reminder of how much we all can learn from each other.

*This AAC alphabet was submitted by Barbara Rush of the Hamilton-Wentworth Communication Collective.
The ABC's were created by Joan Tressel, Augmentative Communication Resource Teacher, Hamilton Board of Education,
as a reminder of teaching strategies to be used with AAC students.*

ABC's for using Augmentative Communication Too **(Symbols, Signs, Communication Displays, Objects, etc.)**

Accessibility - keep augmentative materials
within easy reach and eyesight.

Begin using augmentative materials
in activities and routines throughout the day.

Create a communication environment that facilitates
and promotes the use of augmentatives.

Drill symbol placement and recognition
so that the drill is meaningful
and relevant to class activities;
not just "show me the..." but try
"Show me what you want"
"Show me where you want to go" etc.

Expectations — keep them high but reasonable!
Everybody can use it.
Engineer the environment for maximum
use of augmentative materials.
Excellent tool for expressive language.

Fun, flexible and functional.

Go for it"; augmentatives can be used in
Games and with Groups of kids.

Have your augmentative materials **H**andy.

I — make augmentatives **I**nteresting to use.
Incorporate into all areas of programming.

Jump in !
Just try to use augmentatives
in one more situation each day.

Keeep it simple.

Lots of practice and use.

Model use of augmentatives.
Modify materials as needed.
Make materials manipulative;
introduce in Meaningful context.

Note and record new augmentatives needed.
Note additional needs;
introduce in **N**atural context.

Open minded, **O**riginal, **O**rganized.

Portable, **P**ractical, **P**ositive.

Questions — keep them open-ended.

Resourceful — no picture on the display? Make one up.
Remember to use augmentatives as a **R**eceptive
language tool.

Simple, **S**nappy, **S**ensible (use what you need.)

Talk, **T**alk, **T**alk!
Try to use augmentatives in many different
situations with many different people.

Useful tool — **U**tilize available resources.

Variety — encourage **V**erbalization when possible.

Work into classroom routines / activities.
"Wait" for responses.

X Y Z — sky is the limit !!!

My Life with Bliss

PAUL SULLIVAN

Paul Sullivan has just become the recipient of the Hamilton-Wentworth Communication Collective travel scholarship. This scholarship will enable Paul to attend the 6th Biennial Conference of the International Society for Augmentative and Alternative Communication (ISAAC) in the Netherlands this Fall. Congratulations Paul! We look forward to publishing your thoughts on the conference when you return to Canada.

Home has been many places. I lived in my parents' home until I was approximately three, then moved to Huronia Regional Centre till I was thirteen. I was placed in the Good Samaritan Hospital until I moved to Participation House Brantford at the age of twenty-seven. I am now forty-two.

I have cerebral palsy and am completely non-verbal. I was twenty-eight when I first learned Bliss. Augmentative communication is divided into three areas of my life – past, present and future. That is how I'll tell my story.

Past

The only way I could communicate was through sounds, eye movement, pointing and small movements of my head and body. Thoughts were in my head, but I could not communicate to workers. I felt angry, sad, upset and afraid. I screamed when I was angry because I could not communicate with Blissymbols. The staff, my family and friends did not know what I was trying to say.

When I moved to Participation House, I think staff thought I was not smart. Staff did not think there was much hope for me. They did not spend much time with me; they did their job and left. A special friend, Mr. Al Nicholls, saw hope for me.

Present

Al taught me to use Blissymbols, and I learned them fast. People were surprised and my family was happy.

I feel happy and better about myself. I feel special and proud. It feels good to communicate to workers with Blissymbols. I can communicate what I want to say.

The most important thing is my independence.

When Participation House got the Talking BlissApple software, I learned to use it. I wrote letters to my sister in the United States. She would send letters back in Bliss so I could read them. I wrote letters to my hero, Wayne Gretsky. I also sent memos to staff if I needed to tell them something. It saved time.

I go many places and do many activities. My communication has helped me do many things. I go to meetings and "speak" to the other members. I was honorary chairperson for our Telethon and had to participate in committee meetings.

I took the Targeting Horizons for Adults in Transition (THAT) course at Mohawk College. I would not have been able to go if I did not communicate well.

I go to gatherings now, and can communicate with others. I was a

volunteer with another Bliss user at Brantwood. I talk to other members of my church. I work in the P.H. Tuck Shop.

I had a problem: I drooled a lot and it was always on my Bliss display. I found out that there was an operation to help control drooling. I requested (through Bliss) to see the specialist. The doctors said I could have the operation because I was a good candidate. The drooling interfered with my communication, and that was important in my life. The operation was successful and has helped me feel better about myself too.

The most important thing is my independence. I was chosen to live in an internal apartment to learn skills for independent living. My communication has helped me become more independent and confident in myself. I do my banking, book my transportation and plan my outings.

Future

In 1993, I got a computer. I can write messages, save them and print them. I have a modem, but I have not used it yet. I want to use it to send letters to my sister in Oklahoma.

I want to meet new people. My goal is to live in a group home in the community. Since I have learned Bliss, I have been able to feel proud, lucky and good about myself. I want to be able to teach children Blissymbols.

Everything is happening in the field of Augmentative Communication. I am proud to be a part of it. I feel excited about the future.

Communication Board Used in South African Courts

FAIZAH TOEFY

Thanks to Annalu Waller for sending us this article. The author, Faizah Toefy, graduated in 1991 with a B.Sc. (Logopaedics) at the University of Cape Town and now works at a school for children with cerebral palsy.

It cannot be said with certainty that a communication board has never been used before in South African Courts. However, judging from the resistance to the use of an alternative communication mode for a severely handicapped person, it is definitely still a foreign concept.

In a recent case where a fifteen-year-old non-speaking girl, Thandi, was sexually abused, great difficulty was experienced in convincing the legal team that she was able to provide reliable evidence using her communication board.

The first problem encountered was that the legal teams handling the case assumed that her inability to speak could be equated to mental insanity. The prosecuting attorney was on the verge of using mental insanity as a basis for prosecution. He felt that it would be easy to prove that it was rape because a mentally insane person cannot give consent to sex. This would also mean that it would not be necessary for her to give evidence and there would thus not be a need for us to find an alternative way for her to testify. When I expressed shock and disgust at his conclusion about her mental state he answered, and I quote: "But I thought you said she cannot speak." In an attempt to ascertain Thandi's level of functioning, the prosecutor asked me if she

knew the difference between right and wrong and how she would explain these concepts if asked in court. He got a better picture of her abilities when I explained what level of mathematics and content subjects she was doing at school. Even after being informed that she was definitely not insane and could hear perfectly well, there was still hesitation from the legal teams to speak directly to her. Throughout the case, surprise was shown when she interacted with others and responded appropriately to normal conversation. The only alternative means of communication known to the court was the use of a manual sign system for the deaf. Introducing the Bliss board to the court thus presented a second problem in this case. It was difficult for the court and the legal teams to understand that someone who was unfamiliar with Bliss could communicate via the Bliss board by reading the word below each symbol. Because of this the court initially felt that I was the only one who could act as mediator. Preparation for the trial included extensive counselling and role play for both Thandi and myself. On the day of the trial however, it was stated that the law required a neutral mediator. This meant that I could no longer act as the mediator. They disregarded the psychological effect that this last minute change could have on Thandi's testimony. The court was unable to find what they termed "a trained neutral mediator" who was familiar with Bliss symbols. They therefore considered the possibility of having Thandi write the answers, postponing the case until a suitable mediator could be found, or not having her give evidence at all. Considering the psychological trauma that the girl had already experienced, the girl's family and I felt that it was neces-

sary for the trial to be completed on that day. In consultation with Thandi, it was reluctantly agreed to use the court's social worker as the mediator. After a short period of time the mediator was able to grasp the concept of the communication board and Thandi successfully gave evidence. At this stage however, it must be stressed that an unknown mediator may not be successful in all cases. In this case Thandi had direct and precise selection of symbol/words or letters using her finger and her language and literacy skills were adequate for an unfamiliar person to interpret.

Another problem that was experienced was the inclusion of vocabulary specific to the sexual abuse onto the board. Legal advisors felt that it may be seen as leading the witness. However the spelling of these words would have been too time consuming. These, together with related words were added to the board to dispel the argument that the witness was being led or prompted.

This case has highlighted the fact that the legal system in South Africa does not readily accept that handicapped people are fully capable of giving reliable evidence in a court of law. It is thus the responsibility of people who work with or deal with the handicapped to insist that all avenues be explored to ensure that even the most severely handicapped are heard in the South African courts.

Despite all these hurdles, we succeeded in demonstrating to the court and convincing them that Thandi, a disabled person, was able to give reliable evidence. At the end, it was satisfying and encouraging to know that the court accepted and used her evidence to jail the accused for a total of ten years. I hope that this experience of mine will help and encourage others who find themselves in similar situations, to persevere.

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Two Roads Can Meet

PAUL MARSHALL

Hello once again from Paul's Place. I have another hot topic for you and I have invited Suzanne Clancy to join me as guest contributor.

Suzanne is an instructor at Mohawk College in Hamilton, Ontario where she coordinates and teaches the Targeting Horizons for Adults in Transition program. Suzanne developed the program in 1980 and I was one of her students, class of '86. I have invited Suzanne to come to Paul's Place to discuss professional/consumer relationships.

Paul: Suzanne, I will begin by saying that we are living in an age where the "equality voices" are almost to the point of being overwhelming.

Suzanne: Paul, what do you mean by "equality voices"?

Paul: Suzanne, to me "equality voices" are the voices that are demanding to be integrated into the normal stream of society regardless of the cost required to accommodate the needs of the individual.

Suzanne: Paul, I find that a fascinating statement, especially coming from someone who I feel has been denied less than full participation in society. I would think that you, of all people, would be an ardent advocate for meeting the full integration needs of all people, irrespective of the cost in money, effort or time.

Paul: Well Suzanne, I am for integration where it is for the benefit of the person who is being integrated. If it doesn't serve the needs of the person, however, then integration becomes segregation as far as motivating the AAC user to become a member of society. To me this is disempowering rather than empowering.

Suzanne: Frankly Paul, I have never considered the concept in this way before. You have certainly given me something to think about. Like so many of your thoughts and ideas, I think you are right in stating that something that does not benefit the user is disempowering. It causes me to reflect on my own work at the College. My goal has always been to enhance the learning and the quality of life for what I have long felt was a disenfranchised group. I think(hope) I have done that to some degree. However, you force me to contemplate the true nature of what I do professionally, given fiscal constraints, technology (or it's lack), and the ever changing perceptions and demands of society.

Paul: It would seem reasonable to me that if we are going to have full integration we must work more closely with the various consumer groups. We must do so in a spirit of open communication, cooperation and partnership. Only then can we come together in an effort to best decide what is most effective, desirable and possible, as individuals and as a society.

I agree that we are interdependent. By this I mean my quality of life depends on countless other factors, as does yours. When we are talking about being integrated or having equality in our lives, we must get to the stage where we develop a com-

mon view in our professional consumer relationships. Professionals and consumers should not be viewed as two groups working independently but as one group working on the same ultimate goal—to make *everyone's* life better. We need to re-evaluate the consumer-professional relationship.

Suzanne: Now you want me to re-evaluate my professional self again! Who's side are you on Paul? I just said I agreed with your idea of integration needing to be of benefit to the consumer. Otherwise it would be disempowering. Is there no pleasing this man? O.K., I'm game. In what way do you see the need to re-evaluate the professional/consumer relationship?

Paul: Suzanne, I am not asking for the moon here! All I am stating is whether we are "professionals" or "consumers", we cannot assume anything with a narrow view on "the way it should be". We can't discount the ideas of either group.

Suzanne: Here! Here! Music to my ears. Is it possible that you and I have come to a fork in the road and have chosen the same path? Now what do we do to get others to follow?

Paul: Well Suzanne, I can see this is going to take more than one column to discuss. Would you be willing to come back to *Paul's Place* in September so we can follow-up on what we have begun?

Suzanne: Paul, I would welcome the opportunity to chat with you again. I agree we have much to discuss.

Paul: Why don't you, dear readers, join the discussion? Write me in care of:
Communicating Together.

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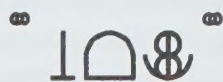
Being Human First

SHIRLEY McNAUGHTON

Readers should be warned that the following article is more aptly titled "*Personal Perspective*" than "*SymbolTalk*". We had not planned to include *SymbolTalk* within this issue of **Communicating Together** because of my being out of Canada during April and May, collecting data for my Ph.D. thesis. As the time for publication approached, however, I decided there were things I really wanted to say on the topic of professionals. Why not offer a personal perspective in *SymbolTalk*, acknowledging that symbols have an influence upon everything I say and write? So, for this one issue, here is *ShirleyTalk* — and look for the return of *SymbolTalk* in September!

Persons and/or Professionals

Having knowledge and skill derived from a liberal, scientific or artistic education and being paid for one's work would seem to be the critical points contributed by the dictionary definition for the *professional* context I am addressing here. Because this is *SymbolTalk*, I offer my combined personal Blissymbol for the dictionary definition: *person* + *knowledge* + *payment* (contracted from *to pay*). (See insert.) As I will discuss later, I believe one component is missing. I will present a revised symbol later in this article.

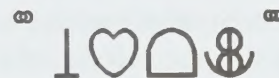


Those with whom I have worked over the years will know that I have had trouble with some of the concepts surrounding "professionalism". I am very saddened whenever I see the professional role masking or negating the professional's personal ethics and standards. I can best illustrate my view through describing where I would want the symbol for *professional* to appear if I used a symbol board. My display would have the *person* symbol appearing prominently at the top of a section, with the members of the person category positioned below it. *Person* would stand out as the classifier; *professional* would be one member of the *person* set — an example of one of the many roles a person could play.

I consider myself very lucky! I entered the professional world after developing a partnership and building a home with my husband, beginning to raise two sons, working in the business world, volunteering and initiating new services in the community and having many opportunities through academic study and within a Unitarian congregation to think and learn and to develop and apply a strong belief system. Attempting to help others gain the opportunity for choice that I wanted for myself became a way of life. When I entered Teachers' College, I brought my strong belief system with me. I was keen to acquire the professional knowledge and skills that could expand and enrich what I could do *as a person*.

What I came to expect of myself as a professional has influenced what I now expect from other professionals. Of course, I want to be sure they are competent in the skills of their profession. But the essential factor in my relationship with any profes-

sional is what they are like as a person. I want the professional to be a caring, compassionate, considerate individual who is not arrogant, does not discount my knowledge of my capabilities or my condition and is prepared to enter into a collaborative goal-oriented relationship with me. If I can trust and respect them, I can be assured they will not misrepresent their skills and knowledge. Without trust and respect, their skills and knowledge are irrelevant. To emphasize the critical feature of a professional, for me, I would add one component — *feeling* — to my previously offered symbol for *professional*.



Organizations & Professionals

I have had many years of being a team player or team leader within organizations. Whenever a policy determined by financial and organizational priorities was imposed upon team decisions, I had to rely on the professionals within the team, as persons, to strenuously support the interests of their client. They or I had to fight vigorously for standards which placed the needs of individuals first. In the May, 1994 issue of *Augmentative Communication News*, Sarah Blackstone reported on the final session of a symposium entitled "Transitions: Visions On Near Future Developments in the Field Of Rehabilitation" held at the Institute for Rehabilitation Development and Knowledge Transfer in the Fields of Rehabilitation and Handicap, Hoensbroek, The Netherlands, in April, 1994. The speakers talked

about "the importance of providing a continuum of options for persons with disabilities *tailored to meet their needs rather than the needs of institutions, companies or professionals* (italics added)" (p.8). I would only wish to add, professionals must be strongly involved in the process of change required to meet this goal!

I am always saddened when governmental or organizational policy intrudes on the relationship between professionals and the individuals they serve. Whenever I hear that a professional's caseload is too large to see individuals often or long enough, that funding restrictions and authorized equipment categories limit the devices available to an individual regardless of his or her needs and abilities, that a communication system is being recommended in order to meet the needs and the limitations of the professionals in the individual's setting rather than matching the abilities of the individual, that funding sources or services are fully assigned for this year and individuals should try again next year, I feel for the individuals whose service is being compromised. I feel as well for the professionals who are required to work in this situation and deliver these messages. I have special empathy for those who must expend energy creatively circumventing restrictive procedures.

Most of all, I am saddened by those who settle for working within the limitations of their organization. I am saddened because professionals whom I highly respect as individuals, must provide a service which does not reflect their personal best. They have many reasons - "lack of thinking time", "too large a case load", "the team not supporting their recommendations", "the person assigned to do follow-up work not being adequately trained or informed", or "the particular service function belonging to another indi-

vidual or agency", etc. The personal integrity of the professional is replaced by organizational policy and we are all the losers!

That many professionals are fighting their administration or finding ways around the rules of the organization that employs them in order to be the professionals they wish to be, is a strong reminder to me of the systemic changes that are needed. How sad that professionals must expend so much energy in a struggle to maintain high personal standards within their professional roles. How sad that in this decade professionals must give more of themselves than their organization will support, if they are to meet the needs of their clients! How sad that many professionals gradually give up their personal values within their work situation, often without even realizing it.

I wish that governmental and organizational support could always be supportive of the highest service professionals can offer, but until this is so, I urge professionals to be their own "person" with those they serve, whatever that may mean - working overtime, making an extra trip to their client's home on their own time, paying their own way to a conference that will give them new knowledge, going out of their way to bring assistance or share new information, listening and learning from and enjoying being with their clients. Those professionals who maintain their high personal standards are the ones AAC users need. They are the ones who make a *personal* difference!

Thinking of Oneself

As I write this, I can just imagine the reaction of many readers. "Boy, what an idealistic dream!" "Does she want us to give up our personal life for our job?" "How much can one person do?" To those persons I ask

them to think of what they want for their own loved ones and then - to stretch themselves! I recently experienced the loss of my father after he had been in the hospital for just ten days. I was reminded vividly of the situation of my mother whose final eight years were spent in a nursing home following a massive stroke, back in the seventies. For both my parents at the end of their lives, the only professional compassion and caring came from those who gave *themselves*, in addition to their skills. For my mother, it was a nurse who spent additional time with her and did many extras. For my father, it was a health care assistant from a private nursing agency who provided the care that the nurses in the hospital could not give due to their extensive case loads, their rigid schedules and the limited supplies assigned to their floor. In both instances, my trust was placed with persons who gave of themselves much more than was expected, or provided for, within the organizations entrusted with providing health care. In effect, these individuals worked outside the system. The system itself had knowledge and skill but failed to foster or even make provision for the professionals within it to relate as *persons* to the *persons* needing care.

Conflicts

There are many differing perspectives regarding what is expected of a professional. If I shift from a person with expectations of professionals back to being a professional, I can recall many conflicts I have experienced as a professional trying to be a person first. In my early days as a classroom teacher, one situation remains strongly in my mind. I became aware that the single parent of a young physically disabled boy in my class had decided to place her child with the Children's Aid Society for adoption. I wanted to tell a

volunteer in my classroom, who had developed a strong relationship with the boy, of his situation and ask if she and her husband would wish to consider adopting the lad. I knew that they had one adopted child in their family and that my volunteer was extremely capable in working with persons with physical disabilities. I was told by my principal that it would be unprofessional and improper for me, as a teacher, to approach my volunteer on this topic. My role was to teach and not to interfere in what was a social worker's responsibility. As I watched the distress of this boy day by day, I decided to quietly disregard my principal's warning and I spoke to the volunteer, telling her of the boy's situation and giving her the appropriate social worker's name. During the next year, the boy was adopted by this volunteer and her husband, and gained a warm and accepting family. I had the joy as a *person* of seeing the lives enriched of both the boy and the volunteer. This far outweighed the pangs of having been "unprofessional"!

As I look back over the years, the satisfactions have been twofold: Of course, I have enjoyed being recognized and honoured within the teaching profession. But the many, many person-to-person relationships I have had, be they with AAC users, their parents, or professional colleagues around the world, have been the most gratifying! I hope the persons with whom I have associated remember me first as a person they respect and secondly, recall that I happened to provide AAC or educational service within our relationship.

Tackling the Root Cause

How can the individual's needs be humanely met within a professional relationship when the time and resources are determined by governmental and/or private funding and

many of the services are delivered within a top-down organizational infrastructure?

I believe it is important that we look to the root causes of institutionalized professional roles replacing our personal roles within the professional relationship. I know some of the many arguments presented - the benefit of detachment and objectivity, the concern regarding burnout, the need for a balance in one's life. Many of these arguments may have merit for professional roles which do not involve persons serving persons. When it is an individual who is the recipient or partner within a professional relationship, however, the reasons given for replacing our personal standards for those of an institution are not good enough! Recipients of a service must be able to evaluate professionals and count on them first as *persons*.

I well know how demanding it can be to apply one's personal values to one's professional role - to strive to interact with one's clients or students as one would with one's own family members. I also know how inadequate and even harmful professional service can be without high personal standards on the part of the professional! I believe the primary cause of the problem is the allowance of institutional factors to take priority over personally responding to the needs of each person being served. I also believe the root causes must be addressed by professionals motivated by their personal values. Their professional knowledge provides them with unique specialized information. Their personal values must supply the energy to fight for change.

Back to Symbols

It would appear that I have wandered far from symbols, but let me return to them, for a last comment. In *SymbolTalk*, when I place

attention upon the quality of the symbols and direct concern toward the language learning opportunities afforded by symbols to young children without functional speech, I am doing that *person thing* again! I am remembering the speaking and language opportunities I took for granted with my own children and am now witnessing with my grandchildren. As a person performing a professional role, I can never cease to search for the closest approximation of that capability for the next generation of AAC users.

Whatever rationalizations and rhetoric accompany the decisions, there is no doubt that the organizational and financial restrictions imposed upon clinics and schools is having a negative impact upon obtaining appropriate communication systems, adequate care and quality education for AAC users. Fighting for improvement must be undertaken by professional organizations and advocacy groups, but it needs the strong involvement of professionals acting as committed *persons* and collaborating with all the other *persons* participating in the endeavour - especially with those being served by professionals. Given the economic climate of the nineties, the job ahead is enormous!

There must be increased recognition of the needs and rights of individuals, through infrastructure changes and the re-allocation of financial resources to give greater control to the person(s) being served. The hope for major systemic change lies in the actions of many *persons*. In the meantime, professionals must continue to be innovative in finding ways through and around organizational roadblocks. Those who are proficient in doing this are the *persons* I will be looking for!

Reference

- Blackstone, S. (1994). University & Research. *Augmentative Communication News*, 7 (3), 7-8.

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